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**PARTICIPANT CONSENT FORM**

**Title of Project: The BILAG Biologics Prospective Cohort: Long-term Safety of New Treatments in the Management of SLE**

**Name of Researcher: Professor Ian Bruce**

**Please initial box**

1. I confirm that I have read and understand the information sheet dated 19/03/2021 (version 7.0) for the above study and have had the opportunity to ask questions.
2. I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that information held by the NHS and records maintained by The NHS Information Centre and the NHS Central Register may be used to help contact me and provide information about my health status.
4. I agree that my specialist Dr may provide the researchers with information from my Health Records that is relevant to this Study.
5. I agree to information, from which I can be identified, being held by the research team at the University of Manchester, together with data collected during the study.
6. I agree to donate samples for use in genetic and biomarker research, as described in the information sheet. I am willing to gift these samples for research. I understand that DNA and RNA will be extracted from the collected samples.

a) Blood

b) Urine

c) A small amount of my ‘excess’ kidney sample (if I have had or will have a kidney biopsy for my clinical care)

* I agree to donate sample(s) of my excess kidney tissue already stored at the hospital
* I agree to donate future sample(s) of my excess kidney tissue

1. I understand that my blood and urine samples will be stored securely for use in future studies. Storage may take place at the University of Manchester or at a specialist company providing biological storage facilities.
2. (If I donate a small amount of my left over 'excess' kidney sample) I understand that the paraffin block containing my kidney sample may contain information from which I can be identified. I understand that the block will be sent securely to a researcher at Imperial College London, and that the researcher has training and certification in confidential and secure handling of my personal information. I understand that the researcher will anonymise the small piece of my kidney and return the paraffin block securely to my hospital.

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1. I agree that anonymised information about me and my samples may be shared by the BILAG team with other collaborators (academic institutions or commercial organisations worldwide) to perform research that will lead to a greater understanding of the causes of and processes involved in SLE.
2. I agree that any data collected may be published anonymously in academic books or journals.
3. I understand that if I change my mind and withdraw consent from this study at a later date, any identifiable samples or data that have been donated or collected will be withdrawn from the study or destroyed. Any paraffin block containing my kidney sample will be returned to my hospital.
4. I understand that individuals from the University of Manchester, from the regulatory authorities or from relevant NHS Trusts will have access to my personal data in order to monitor and audit the conduct of the study.
5. I agree to allow the researcher to make contact with me about other studies in the future.
6. I agree to take part in the above study.
7. I agree for my GP to be notified about my participation in the study.

Name of patient Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature

*1 copy for patient; 1copy for researcher; 1 copy to be kept with hospital notes*